MERCER COUNTY

Cancer Control and Prevention Capacity and Needs Assessment Report Summary

December 2004

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Notices:

Medicine is an ever-changing science. As new research and data broaden our knowledge, conclusions may change. The authors and reviewers have endeavored to check the sources of information and to utilize sources believed to be the most reliable in an effort to provide information that is as complete as possible at the time of submission and generally in accord with appropriate standards. However, in view of the possibility of human error or changes in medical science, this work cannot be warranted as being complete and accurate in every respect. Readers are encouraged to confirm the information contained herein with other sources. Information concerning some of the sources of data, rationale for its utilization, acknowledgements of specific parties contributing to these efforts, as well as links to cancer-related information may be found at www.umdnj.edu/evalcweb/.

This county-level Report Summary summarizes the larger county report, which is a baseline evaluation of this county, performed as part of the Capacity and Needs Assessment initiative of the New Jersey Comprehensive Cancer Control Plan (www.state.nj.us/health/ccp/ccc_plan.htm), under the direction of the New Jersey Department of Health and Senior Services (NJDHSS) Office of Cancer Control and Prevention (OCCP) (www.state.nj.us/health/ccp/), the University of Medicine and Dentistry of New Jersey (UMDNJ) (www.umdnj.edu/evalcweb/), and the Evaluation Committee of the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force Chair: Arnold Baskies, MD; Evaluation Committee Chair: Stanley H. Weiss, MD).

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Mercer County Cancer Capacity and Needs Assessment Report Summary

Introduction

The Office of Cancer Control and Prevention (OCCP) of the New Jersey Department of Health and Senior Services (NJDHHS), in conjunction with the mandate from the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force), is developing comprehensive capacity and needs assessment reports concerning cancer, individualized for each county in the state. This Report Summary highlights key findings in the Mercer County Report.¹

The Task Force released New Jersey's Comprehensive Cancer Control Plan (NJ-CCCP) in 2002.² Each county was commissioned to develop a comprehensive capacity and needs assessment report, as part of the initial implementation steps for the NJ-CCCP. The full Report and this Report Summary were developed under the direction of the University of Medicine and Dentistry of New Jersey (UMDNJ) and the Evaluation Committee of the Task Force, in furtherance of the NJ-CCCP (which can be found at:

http://www.state.nj.us/health/ccp/ccc_plan.htm
htm). This particular assessment was funded by the OCCP and conducted under the contract and direction of the New Jersey Cancer Education and Early Detection (NJCEED) agency in Mercer County: Brava/Colorectal and Prostate Screening (CAPS) NJCEED at Capital Health System at Mercer, Trenton.

The purpose of the capacity and needs assessment reports is to identify the major cancer issues affecting each county and the county's available resources, or lack thereof, for cancer prevention, screening, and treatment, and to propose recommendations for improvement. The Mercer County Report¹ analyzes the population demographics and the cancer incidence and mortality rates and distribution of stage at diagnosis for the seven priority cancers of the NJ-CCCP (breast, cervical, colorectal, lung, oral, melanoma, and prostate), as well as the current resources available, in the county. These data guided the development of evidence-based recommendations and interventions to address cancer control priorities at local and state levels.

Section 1 – County Demographic Profile

Mercer County located in the southwestern portion of the state comprises only 228.84 square miles. Highlights of the county include:

- The county's population density (1,552.5 population per square mile), 8th highest among New Jersey's 21 counties, is slightly higher than the state's population density (1,134.4).³
- Mercer County has 13 municipalities, with population sizes ranging from 2,035 to 87,109 residents. The adjoining Township of Hamilton (87,109) and the City of Trenton (85,403)

comprise almost one-half of the total population of the county. The smallest municipality is Hopewell Borough with a total population of 2,035 residents, and the municipality with the highest population density is Trenton City (11,153.6 people per square mile).³

• Although there is public transportation within the county, most of the population (73%) drives to work or school. a,4

Population

Mercer County's total population of 350,761 is evenly distributed between males and females and has seen a small increase between the 1990 and 2000 Census (7.7%). This growth is less than for the state (8.9%) and the nation (13%).

- The single largest increase in population occurred in the age group of 50 to 54 years, with a dramatic increase of 49% 5
- The percentage of seniors in the county population (12.6%) was slightly lower than that in the state (13.2%). The increase in assisted-living facilities and retirement communities may contribute to an increase in the county's senior population.
- The single largest age group, 25 to 34 years, representing 14% of the population, was also one of only three age groups that showed a population decrease between 1990 and 2000.

Race/Ethnicity

Mercer County's racial/ethnic profile may be characterized as below.

- A smaller population self-identifies in Mercer County as white only (68%) than in the state as a whole (73%).
- A larger population self-identifies in Mercer County as black only (20%) than in the state (14%).
- Almost 10% of the population is Hispanic (9.7%), slightly less than the state percentage (13%). The Hispanic population comprises a relatively large portion of the population in East Windsor Township (14%), Princeton Borough and Township combined (12%), Hightstown Borough (20%), and Trenton City (22%).
- The Asian population in Mercer County comprises 4.9% of the county's population (5.5% in combination with another race or 19,128 residents); 23% of West Windsor Township's residents are Asian.³ Interestingly, this township has the highest median household income (\$116,335) and the highest percentage of residents with education beyond a high school diploma (89%).⁶

The location or clusters of these minority groups is of importance in the analysis of the county's capacity and needs.

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^a In general, percentages in this report are rounded to two digits.

^b Hispanics and non-Hispanics may be of any race. Racial categories include both Hispanics and non-Hispanics.

Language

Even though the county percentage (5.1%) is lower than that of the state as a whole (6.3%), a total of 15,714 people or 6,034 linguistically isolated households exist in Mercer County. Spanish is the predominant language comprising this segment of the population.

Education and Literacy

According to the 2000 Census, over 12% of the population aged 25 and over in the city of Trenton has less than a 9th-grade education, the highest such percentage in this age group for all municipalities in Mercer County (5.9% average for entire county) and nearly double the percentage for this age group in New Jersey (6.6%).⁶

Among those with education beyond 9th grade, Trenton City had the highest percentage of its population aged 25 and over without a high school diploma or equivalent (25%). Other municipalities in Mercer County had percentages similar to or lower than the New Jersey average (11%): Hamilton Township (12%), Ewing Township (11%), Hightstown Borough (9.9%), East Windsor Township (7.4%), Hopewell Borough (7.1%), and Lawrence Township (7.1%).

The National Institute for Literacy reports that 20% of Mercer County's population aged 16 and over is estimated to have a Literacy Level I, meaning that almost all adults in this category can read a little but not enough to fill out an application, read a food label, or read a simple story to a child. People with low literacy levels cannot read pamphlets, directions on a bottle, or explanations for a food exchange list. People with reading problems come from all socioeconomic levels, all ages, and all ethnic backgrounds, and people with poor reading skills may have a difficult time preventing illness and managing their healthcare needs.

Income and Housing

In 1999, the percentage of Mercer County's population with income below the federal poverty level (8.6%) was similar to that of the state (8.5%). In Trenton City, however, 21% of the population was living in poverty (17,222 persons). The municipalities with the next highest percentages living in poverty are Princeton Borough (9.0%), Hightstown Borough (7.3%), Ewing Township (6.4%), Princeton Township (5.7%), and Hamilton Township (4.2%). Hamilton Township has a relatively low percentage of its population living in poverty but the second highest number of persons with incomes below poverty level (3,619) in the county.

A higher percentage of residents in Trenton City (37%) and Princeton Township (34%) pay 35% or more of their household income to rent, compared to the county as a whole (30%) and the state as a whole (32%). ¹⁰

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^c A linguistically isolated household is one in which no member 14 years old and over (1) speaks only English or (2) speaks a non-English language and speaks English "very well". In other words, all members 14 years old and over have at least some difficulty with English.

^d All figures for poverty, income, and employment are from the 2000 Census, but refer to the year 1999.

A Community Profile of Trenton

Trenton is home to a total population of 85,403 residents that is more ethnically diverse and disproportionately poorer than other areas of New Jersey and the nation.³ Approximately 44,465 Trenton residents are black (52% of the city's total) and 25% of neighboring Ewing Township is black. Trenton's black population is 64% of the county's total black population.

The Hispanic population also constitutes a substantial proportion of the city's residents (22%). Trenton (and neighboring Lawrenceville) also has a large Polish and Eastern European population estimated at 6.4% and an Italian population estimated at 7.3% of the total municipality.

Key Demographic Aspects of Trenton

- **Poverty.** In 1999, of the population with incomes below the poverty level in Mercer County, 60% lived in Trenton City; this population with incomes below the poverty level was 58% black and represented 21% of the total population of Trenton City, more than double the state average.¹¹
- **Employment.** One-fourth of Trenton residents (26%) worked in service sector jobs that typically have lower salaries and fewer health benefits, compared to 14.3% of the county and 13.6% of the state. The unemployment rate for Trenton is 10.5% compared to 7.5% in Mercer County and 5.8% in the state. The unemployment rate for Trenton is 10.5% compared to 7.5% in Mercer County and 5.8% in the state.
- **Education.** Trenton has the highest percentage of its population with less than a high school diploma (38%);⁶ generally, municipalities with higher percentages of minority residents and poverty have lower levels of education.
- **Household structure.** The county has a slightly higher percentage of female householders with children and no husband (13.8%) than does the state (12.6%). Almost one-half (46%) of these households are located in Trenton City; 27% of the city's households meet that description. The higher percentage of female householders with children but no husband in Trenton City may be a contributing factor to the lower median household income (\$31,074), which is approximately 250% of poverty level for a family size of two.
- **Teen birth rate.** In 2000, 8.6% of all live births in Mercer County occurred among teenage mothers (ages 15 to 19 years), slightly higher than the statewide percentage (6.9%). The county's teen birth rate was 32.9 per 1,000 females, which is similar to the state rate (31.6 per 1,000 females); In Trenton, however, the teen birth rate was 99.5 per 1,000 females, third highest among selected municipalities in the state.

Concluding Points

• In 2000, Mercer County had a 3% higher age-adjusted death rate due to all causes (879.0 per 100,000) than did the state (852.4 per 100,000). ¹⁴

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^e Unemployment rate is based on the population 16 years or older in the civilian labor force.

- Trenton City was the fifth highest municipality in the state in terms of the total number of substance abuse^f treatment admissions and the second highest for alcohol-related treatment admissions in 2001.¹⁵
- The percentage of the population that smokes in Mercer County is not available; however, the Behavioral Risk Factor Surveillance System (BRFSS) trend statistics for New Jersey indicate that approximately 21% of male adults and 18% of female adults in New Jersey smoked in 2002, with decreasing use by age. In New Jersey, approximately 21% of the white population and 18% of the black population reported smoking. Data from the BRFSS also indicate that those with lower income or educational attainment are more likely to smoke than those with higher income or educational levels.
- Mercer County is a county of those who "have" and those who "have not." One example is the dramatic differences in income and allocation to housing costs. Trenton City and West Windsor Township represent the county's two extremes. Trenton City residents had the lowest 1999 median household income \$31,074 of any municipality in the county, while West Windsor Township residents had the highest 1999 median household income in the county \$116,335. Yet in Trenton, the median annual gross rent of \$7,248 was 28% of renters' household income, while in West Windsor Township, the median annual gross rent of \$14,376 was only 21% of renters' household income. Trenton City residents had the lowest median household income and thus have less expendable income, and yet had the highest percentage of its population paying at least 35% of their income to rent.

Section 2 – Overview of Overarching Issues

Mercer County has a wealth of resources within its community, although the county does not have a comprehensive plan or county health department to address the cancer burden.

The National Cancer Institute's (NCI's) Atlantic Region Cancer Information Service (CIS) provided Consumer Health Profile maps of Mercer County, which identified 105,269 county residents who are medically underserved. The term 'medically underserved' refers to individuals who lack access to primary care either because they are socioeconomically disadvantaged and may or may not live in areas with high poverty rates or because they reside in rural areas. Within Mercer County, many of the medically underserved clusters are located in the Greater Trenton City area, with sections of Trenton and its neighboring communities in need of breast, cervical, colorectal, and prostate cancer screening and smoking cessation services. Based on data from the New Jersey Primary Care Association, the lack of dental health and

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f Includes alcohol, heroin, cocaine, marijuana, and other drugs.

^g The National Cancer Institute's Atlantic Region Cancer Information Service provided Consumer Health Profile maps of each New Jersey county, along with ongoing technical support, to the NJDHSS and UMDNJ and each county in June 2003. (More information can be obtained from: 1-800-4-CANCER.)

^h The term *medically underserved* also refers to individuals who reside in geographic areas where the Index of Medical Underservice (IMU) is 62 or less. The IMU is a weighted score derived from four variables: the ratio of primary medical care physicians per 1,000 population, infant mortality rate, percentage of population below the federal poverty level, and the percentage of the population aged 65 years and older. The data categorize the U.S. population into 62 groups based upon characteristics such as geography, demographics, lifestyle, and socioeconomic status. Within these 62 groups, 30 are classified as medically underserved.

primary medical care services have been identified as problems in multiple census tracts within low-income Trenton and most of the surrounding communities.¹⁸

Lack of Access to Healthcare Resources

Several factors contribute to lack of access to healthcare resources in the black, Hispanic, and low-income populations. These include transportation, socioeconomics, lack of health insurance, cultural and belief systems, and household structure (e.g., single mothers and grandparents as caregivers). An overview of these barriers is presented below.

Transportation

Many primary care providers have migrated to the suburbs, requiring those within the inner cities to travel in order to obtain medical care. Transportation is costly and difficult to navigate, especially for a compromised patient. The American Cancer Society offers volunteer-based transportation services to cancer patients and their families, and many faith-based organizations also provide transportation services for members of their congregation. However, most county or municipal resources for free or reduced fare transportation are available for seniors only.

Socioeconomics

Low-income populations are particularly affected by loss of income as a result of taking time off from work for medical appointments. Lack of childcare is an important issue for single mothers and grandparents who are the primary caregivers. Of the estimated 7,141 grandparents in Mercer County living in a household with one or more own grandchildren under age 18, approximately 35% or 2,506 grandparents were primary caregivers in 1999; over one-half (1,439 grandparents) lived in Trenton alone. ¹⁹

Health Insurance

In New Jersey, 29% of Hispanic, 23% of black, and 22% of Asian residents were estimated to be uninsured in 2000. The age group with the highest percentage of estimated uninsured was adults aged 19 to 24 years (26%). Lack of health insurance can cause economic hardship for those seeking health care services. In addition, the lack of health insurance for county residents and inadequate charity care reimbursement place economic burdens on the county's hospitals, which may result in decreased or no funding for other cancer programs.

Cultural Barriers and Belief Systems

Fear remains a barrier to receiving medical care in the black community, according to key informants. Knowledge is power; however, the perception that racial minorities do not receive the same level of care adds to the fear preventing people of color from seeking care proactively. Within the Asian communities, possible distrust of Western medical practices, professionals, and medicine may affect a patient's awareness of cancer information and may represent a barrier to accessing medical care. 22

Language and Literacy

A language barrier affects the ability of the resident to access medical care and ultimately navigate the health care system and understand medical advice. Illiteracy is another obstacle to healthcare access.

Resources

Detailed information regarding cancer screening, education, advocacy, treatment, palliation, and other activities has been collected to identify resources currently available in Mercer County. This information was included in the statewide Cancer Resource Database of New Jersey (CRDNJ).²³ Over 190 agencies participated in the 2003–2004 Cancer Resource Database of New Jersey (CRDNJ) survey.²³ This section provides a summary of resources available in the community to address cancer needs based upon responses to the survey.

Employers

There are many major employers (employers with more than 500 employees) in Mercer County; most of the employers that responded to the CRDNJ survey (71 of 361 total) indicated that they offer some cancer screening and health prevention programs, either on-site or through affiliation with a provider. Some offer memberships to health and wellness centers at reduced fees.

Faith-Based Organizations

There are approximately 258 faith-based organizations in the county. Black churches in Trenton are a galvanizing force in healthcare prevention for their constituents.

Community-Based Organizations

The American Cancer Society (ACS) and Trenton's Mayor Douglas H. Palmer have made a commitment to reduce cancer disparities in the city of Trenton by implementing the "Trenton Crusade against Cancer" Initiative. Through partnerships with local corporate leaders, healthcare institutions, faith-based and community-based organizations, the Initiative seeks to create a plan to expand education and awareness, increase cancer screening rates, improve access to transportation, and promote a clean indoor air policy. There are several community-based organizations in Mercer County dedicated to raising cancer awareness, providing education, fundraising for cancer research, and providing support for cancer patients, survivors, and their families. The ACS is a nationwide, community-based voluntary health organization dedicated to helping everyone who faces cancer through research, patient services, early detection, treatment, and education, which maintains a useful website and national call center (1-800-ACS-2345, ext. 1). Patients and others can obtain referrals to local cancer resources as well as to a local "patient and family services director/coordinator" who may be able to serve as a "patient

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ⁱ The national call center takes 1.2 million calls per year. See http://www.cancer.org/docroot/ESN/content/ESN_3_1X_ACS_National_Cancer_Information_Center.asp?sitearea=ESN (accessed 9/22/2004).

navigator." Mercer County is part of the ACS Central Jersey Region, which is a major partner in community outreach, education, and screening referral throughout the county.

NJCEED Program

Brava/CAPS NJCEED located at Capital Health System at Mercer, Trenton, provides breast, cervical, colorectal, and prostate cancer screening to low-income (below 250% of the federal poverty level) and uninsured or underinsured residents of the county.

Health Departments

There are eight health departments in the county; some departments cover two municipalities. Most departments participate in health fairs and offer cancer screening, education, and referral. The Lawrence Township Health Department has an existing affiliation with the Cancer Institute of New Jersey and offers all services free of charge.

Freestanding Healthcare Facilities

Henry J. Austin (Trenton), a non-profit 501(c)(3) corporation, has provided comprehensive primary care and most importantly dental care for the Greater Trenton area for over 30 years. This is also the only federally qualified health center in Mercer County.

Planned Parenthood has three clinics in Mercer County (Hamilton, Hightstown, and Trenton) and offers cancer screening, primary care services, and health education.

Veterans Health Administration of the Department of Veterans Affairs (VA) provides health benefits to veterans and their families. Trenton Community Clinic, part of the New Jersey Veterans Healthcare Network, is a satellite outpatient clinic, and all diagnostic evaluations are performed outside of the county.²⁵

Schools

The Comprehensive School Health Education section of the full Capacity and Needs Assessment Report outlines the New Jersey Core Curriculum Content standards and summarizes the health education provided by the school districts that responded to the survey (10 of 11 total). Each school district interprets the standards differently. Some school systems such as West Windsor-Plainsboro report close adherence to the standards and offer additional programs such as REBEL (Reaching Everyone By Exposing Lies, a youth-led anti-tobacco movement); others address topics superficially. All 10 school districts responding to the survey reported that smoking/tobacco, alcohol, and drug use prevention were taught. It appears that there is no mandate for sun protection guidelines; this would be an appropriate issue to address on the local level.

Hospitals

There are five major hospitals in the county that provide cancer prevention, screening, treatment, and referral. These hospitals are Capital Health System (CHS) at Fuld and Mercer, Robert Wood Johnson University Hospital at Hamilton (RWJUHH), St. Francis Medical Center in Trenton, and University Medical Center at Princeton (UMCP). Additionally, Capital Health System and RWJUHH participate in oncology clinical trials. There is no regional cancer center in the community, but the county is in close proximity to the Cancer Institute of New Jersey (CINJ) in New Brunswick and cancer centers in the Philadelphia, Pennsylvania area. All hospitals provide cancer support groups; CHS at Mercer and Fuld and RWJUHH have particularly strong support groups.

Hospices

There are four hospice programs that provide care to the county; two are located outside the county in nearby Monmouth. Initial consultation generally occurs within eight hours of contact. All programs accept all insurance, Medicare, Medicaid, and charity care.

Advocacy

At the state level, the New Jersey Legislative Priorities for 2003 include (1) support for the comprehensive cancer control plan, (2) reduction and prevention of suffering related to tobacco illness, and (3) increasing access to cancer care, prevention, and awareness programs. At the county level, the ACS provides internal structure and funding for cancer awareness, education and early detection programs, and access to care. The local county chapter is located in Lawrenceville.

Various cancer awareness, education, and early detection programs, as well as programs addressing access-to-care issues, are planned at the county level, including the annual "Run for Dad" (prostate cancer awareness) and "Relay for Life."

The current "Call to Action" in December 2003 is for "Support Clean Indoor Air for New Jersey." The New Jersey legislature is considering legislation that would ban smoking in all places of employment throughout the state, including restaurants and bars.

Reducing Cancer-related Health Disparities among Minorities and the Medically Underserved

The disproportionate burden of poor health and cancer within the black and Hispanic communities of Mercer County (especially Trenton) has been acknowledged by various advocacy groups. The Trenton Initiative, a collaborative group working with various outreach organizations such as ACS, NJCEED, local health departments, and hospitals, has been established to achieve the ACS goal of eliminating the unequal burden of cancer.

The Concerned Pastors Economic Development Corporation (a non-profit consortium of 35 member churches) and the Mayor of Trenton are committed to reducing the unequal burden of cancer felt by diverse communities like the city of Trenton.

Within Trenton, the Healthier Lifestyle Institute was recently initiated through the Mt. Zion Neighborhood Economic Development to address disparities in the health status of minorities within the City of Trenton. The Institute developed a linguistically/culturally appropriate health education seminar series for Trenton City and Mercer County residents, addressing prevention and awareness of the top chronic illnesses, treatment and compliance, nutrition, and participation in local clinical trials.

Lobbying Efforts

In some cases, individual healthcare providers have hired professional lobbyists to promote support for the programs they offer. For example, large private healthcare providers such as UMCP lobby for funding for their special programs. Several state legislators, representatives, and senators have various health interests and focused health agendas. For example, one representative has authored a bill for mammograms for women under the age of 40; a senator is particularly interested in cervical cancer screening and treatment coverage, and a freeholder is involved in the Pink Ribbon Affair for breast cancer.

The Concerned Pastors consortium is politically active in lobbying for their community. The pastors have shown interest in cancer screening programs within their churches and local centers, including cancer information in their sermons at least monthly, and involvement with various coalition groups (Trenton Crusade against Cancer, Trenton Initiative). The pastors also lobby in the political arena for the medical needs of their constituents.

Nutritional and Physical Activity

Almost 38% of adults (aged 18 and over) in New Jersey are estimated to be overweight, and 19% are estimated to be obese, based on body mass index (BMI). Based on the statewide percentages, it is estimated that there are over 99,000 overweight and over 50,000 obese adults in Mercer County (based on the number of Mercer County residents aged 18 and over reported in the 2000 Census). Several organizations and hospitals in the county offer nutrition and exercise counseling or programs, including the Supplemental Nutrition Program for Women, Infants and Children (WIC). However, based on a key informant interview, access to these services is a problem for many residents who do not have a private vehicle.

Childhood Cancer

The average annual age-adjusted incidence rate for childhood cancer during the period 1979–1995 in Mercer County (13.7 per 100,000) was slightly lower than the New Jersey rate (14.3 per 100,000). On average, there were approximately 9 new cases of childhood cancer per year during this period in Mercer County and 240 new cases per year in the state. ²⁶ The county does not provide pediatric cancer services; therefore, all case are referred to CINJ, Children's Hospital of Philadelphia, St. Christopher's Hospital in Philadelphia, Tomorrow's Children at Hackensack

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^j Overweight is defined as a Body Mass Index (BMI) between 25.0 and 29.9, using current standards. Obesity is defined as a BMI of 30.0 or greater. BMI is calculated by multiplying the weight (in pounds) by 703, then dividing the result by the square of the height (in inches).

University Hospital, or other cancer centers located in New York City. Referral is influenced by insurance, physician affiliation, cancer site, parents' choice, and distance from home. Palliative care is available through local hospice programs.

Participation in Clinical Trials

Clinical trials are an important aspect of the healthcare system, as they provide information on new treatments, new methods for early diagnosis and prevention, and the impact of cancer on patients and quality of life. Participation in clinical trials can be one avenue to receiving the best available care and would help improve access to care. Unfortunately, black and Hispanic populations are generally underrepresented in treatment and prevention trials.

Women are more likely to participate in clinical trials if they perceive it will benefit others; however, men have more negative perceptions of clinical trials. Specifically, more black than white patients believe that God will determine whether they will be cured or not. The factors of lower education, lower income, and the belief that survival is in the hands of God were independently associated with a *decreased* willingness to participate in clinical trials.²⁷

Within the state and county, several organizations have acknowledged the importance of clinical trials and provide education about clinical trials for the black population and other underserved populations. One such organization is 100 Black Men of New Jersey, Inc., based in East Orange, New Jersey (Essex County). This organization has identified the following barriers to clinical trial participation in minority communities:²⁸

- Fear of outcomes and consequences of being used as "guinea pigs"
- Historical precedence for negative reaction to clinical trials
- Fear of developing complications and new diseases
- General mistrust of medical/pharmaceutical industries

IMPACT New Jersey (Improving Minority & Medically Underserved Participation in and Access to Cancer Clinical Trials in New Jersey) is an educational initiative of the 100 Black Men of New Jersey and the New Jersey Commission on Cancer Research, designed to educate and provide underserved populations – including minorities, the poor, and the elderly – with greater access to clinical trials ²⁹

Section 3 – Cancer Burden

All incidence³⁰ and mortality³¹ rates cited herein are per 100,000 and age-adjusted to the 2000 U.S. population standard⁴. All county and state rates are average annual rates during 1996–2000. For simplicity, the 1996–2000 average annual age-adjusted incidence or mortality rate hereinafter will be abbreviated and referred to as incidence or mortality rate, respectively. The reason the five-year average has been routinely used is that the small number of cases in a single year leads to statistical variations that are not generally meaningful. For U.S. incidence rates, 1999 or 2000 rates were used. Unless otherwise specified, all rates are for invasive cancer only.

Overall Cancer Burden

In New Jersey, cancer was the second leading cause of death in 2000;³² one out of four deaths for all age groups were attributed to cancer.²⁴ Men in the state had a higher incidence rate for all cancer sites combined (628.7 per 100,000) than did women (453.7 per 100,000) during the period 1996–2000.³⁰ In addition, New Jersey men had a higher mortality rate due to all cancer sites combined (261.1 per 100,000) than did women (181.6 per 100,000).³¹ In New Jersey, prostate cancer had the highest incidence rate of all cancer sites among men (194.3), while breast cancer had the highest incidence rate among women (138.5). Lung cancer had the highest mortality rate in the state for both men (74.8) and women (41.6).

These findings for the state are reflected in similar findings in Mercer County. Of the 21 counties in New Jersey, Mercer County had the 7th highest cancer incidence rate (for all sites combined) among men during the same period (636.6 per 100,000), which was only 1% higher than the statewide rate (628.7). Among women, Mercer County had the 13th highest cancer incidence rate (452.4 per 100,000), which was less than 1% lower than the state rate (453.7). For all cancer sites combined, black men had the highest incidence rate in Mercer County (747.2 per 100,000) and the highest mortality rate in New Jersey as a whole (385.2 per 100,000), which is 10% higher than the mortality rate for black men in New Jersey (349.4) and 53% higher than the mortality rate for white men in the county (251.6).

The unequal cancer burden is also evident among black women. In New Jersey, the mortality rate for all cancers combined was 12% higher among black women (202.8 per 100,000) than among white women (181.6). The mortality rate for all cancers combined among black women in Mercer County (211.5) was 4% higher than the rate among black women in the state (202.8) and 19% higher than the rate among white women in the county (178.4). With increasing age, mortality rates increased for all cancer sites combined in both county and state, and black men and black women continued to have the highest cancer mortality rates within the county. \(^1\)

As in New Jersey, lung, prostate, and colorectal cancer represented the greatest portion of the cancer burden for men in Mercer County. Lung, breast, and colorectal cancer represented the greatest portion of the cancer burden for women in Mercer County. Lung cancer was the leading cause of cancer death among men (73.3 per 100,000) and women (37.2 per 100,000) in Mercer County.

Cancers for which county incidence rates were at least 10% higher than state rates include oral/oropharyngeal (male) and oral/oropharyngeal (female). The only cancer for which the county mortality rate was at least 10% higher than the state rate was prostate cancer.

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^k Of the 18 counties with a black population greater than 5,000 persons.

¹ Among men aged 50 years and over, the mortality rate per 100,000 for all cancer sites combined was 1,277.3 among black men in the county, 1,179.6 among black men in the state, and 859.7 among white men in the county. Among men aged 65 years and over, the mortality rate per 100,000 for all cancer sites combined increased to 2,118.8 among black men in the county, 1,989.7 among black men in the state, and 1,525.2 among white men in the county. Among women aged 50 and over, the mortality rate per 100,000 for all cancer sites combined was 651.2 among black women in the county, 647.9 among black women in the state, and 588.1 among white women in the county.

	Estimated Prevalence ^d	Incidence per 100,000 ^e	Mortality per 100,000 ^e	
All Cancers, Mercer County				
Male	5,114	636.6	266.1	
Female	7,762	452.4	180.9	
NJ-CCCP Priority Cancer by Gender				
Breast, female	3,040	140.4	33.1	
Cervical, female	309	9.7	3.1	
Colorectal, male	594	78.4	32.3	
Colorectal, female	840	52.9	20.6	
Lung, male	192	93.0	73.3	
Lung, female	226	52.6	37.2	
Melanoma, male	296	19.8	2.9	
Melanoma, female	330	10.5	1.3	
Oral/Oropharyngeal, male	202	20.5	4.5	
Oral/Oropharyngeal, female	129	7.7	1.7	
Prostate, male	2,132	201.7	36.5	

^a Based upon the NJ-CCCP.

Cancer Burden by Site

Breast Cancer

Breast cancer is the most common type of cancer among women, with 1,330 new cases of invasive^m breast cancer reported in Mercer County during the period 1996–2000 (an average of 266 new cases per year). The incidence rate of breast cancer among women of all races in Mercer County (140.4 per 100,000) was similar to that in the state (138.5). The incidence rate of breast cancer among black women in the county (121.4) was 4% higher than the corresponding state rate (116.5). Within Mercer County, the incidence rate for the disease among white women (147.6) was 22% higher than that among black women. The risk of breast cancer incidence

^b Age-adjusted to 2000 U.S. Census population standards. Age-adjustment is used to describe rates in which statistical procedures have been applied to remove the effect of differences in composition (specifically, variations in age distribution) of the various populations. This is important in order to portray an accurate picture of the burden of cancer, since cancer is known to disproportionately affect persons of differing ages.

^c Rates are average annual rates during the time period 1996 through 2000.

^d Prevalence is the measurement of burden of disease in the population at a particular point in time. Within this report, it represents the number of people alive who have ever been diagnosed with the disease. Prevalence figures given here are rough theoretical estimates, based on a number of assumptions, and computed by applying national prevalence-to-incidence ratios to Mercer County's average annual crude incidence counts for the five years 1996–2000, separately for each gender. Actual prevalence is likely to be of the same order of magnitude as the estimate.³³ ^e Incidence and mortality are gender-specific, age-adjusted annual rates, not counts. A rate at least 10% higher than the corresponding state rate is shown in bold italics.

f "All cancers" represents the sum of all invasive cancer during the time period, not just the seven cancers presented in detail below.

^m In situ cancers are not included in this or other totals.

increases with age. The incidence rates among women aged 50 to 64 years and aged 75+ were slightly higher (6%-7%) in the county than in the state, although this was not statistically significant.ⁿ

Mortality due to breast cancer was also slightly higher in the county (33.1 per 100.000) than in the state (31.3). The most striking difference was among black women, whose breast cancer mortality rate in the county (45.9) was 23% higher than that in the state (37.2) and almost 50% higher than that of white women in the county (31.5) or the state (31.1). The majority of deaths due to breast cancer in both the county and the state occurred among women aged 50 and over. However, a higher percentage of breast cancer deaths among younger women (less than 50 years) occurred among black women in Mercer County (28% of breast cancer deaths among black women during the period 1996–2000) and in New Jersey (21%) than among white women in Mercer County (10% of breast cancer deaths among white women during the same period) and New Jersey (11%). A possible underlying explanation might be that more black women were diagnosed at a later stage in the county than in the state, leading to the higher rate of mortality in the county. Within Mercer County there was a statistically significant difference between black women and white women by stage at diagnosis. A lower percentage of cases were diagnosed in the early stages of breast cancer (64%) and a higher percentage of cases were diagnosed in the late stages (35%) among black women in the county than was the case for white women in the county (69% in the early stages, 27% in the late stages). However, the overall distribution by stage at diagnosis in the county was similar to that of the state, so the increase in mortality among blacks in the county as compared to the state remains unexplained.

The first objective in *Healthy New Jersey 2010*³⁴ related to breast cancer is to reduce the age-adjusted death rate to 21.5 per 100,000 for women of all ages and of all races/ethnicities, as recalculated using the 2000 U.S. population standard.³⁵ The mortality rate among black women in Mercer County was more than 60% higher than the *Healthy New Jersey 2010* target mortality rate for black women (28.5 per 100,000, similarly recalculated).³⁵ These would thus represent ambitious targets for Mercer County and most likely will not be accomplished in the near term. However, a reduction in breast cancer mortality among Mercer County women should be a focus.

The second objective related to breast cancer in *Healthy New Jersey 2010* ³⁴ is to increase the percentage of females aged 40 years and over who received a clinical breast examination and a mammogram within the past two years to 75%, with a preferred endpoint of 85%. Although county information is not available, based on Consumer Health Profiles from the National Cancer Institute's Cancer Information Service, it is estimated that 75% of the county's women aged 40 and over are receiving screening, while approximately 24% are medically underserved. The preferred endpoint to increase screening to 85% may be possible to achieve with community programs focused on lower income, urban residents.

The third objective related to breast cancer in *Healthy New Jersey 2010* ³⁴ is to increase the percentage of female breast cancers diagnosed in the early (*in situ*/localized) stage of disease to

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ⁿ The breast cancer incidence rates among women aged 50 to 64 years was 332.4 in the county and 312.2 in the state. Among women aged 75+, the rates were 495.1 in the county and 464.0 in the state.

^o Early stages include *in situ* and localized, and late stages include regional and distant stages.

75% with a preferred endpoint of 85%. Mercer County's five-year (1996–2000) percentage of cases diagnosed in the early stages was 69%, which is lower than the desired end result. Reaching to achieve the goal set by *Healthy New Jersey 2010* mandates more aggressive mammogram screening. Perhaps mammogram reminder mailings to women over the age of 50^p will serve to remind residents of the importance of screening. Women and healthcare professionals should also be the focus of patient and provider education activities stressing the importance of early detection.

Prevention activities should focus on black women based on their higher breast cancer incidence and mortality rates as compared to the state (46.0 county versus 37.2 state). Dissemination of information on screening facilities, times available (many facilities have evening and Saturday hours), and free programs through Susan G. Komen Foundation and NJCEED, creation of a follow-up system (initiation of a database at the local levels), and outreach to faith-based organizations should be stressed at the county level.

Among 3,923 New Jersey women aged 50 and over who were interviewed from 2000 through 2002, 78% reported having had a mammogram within the past two years. ^{16,36} Based on interviews of 167 women in Mercer County, the county screening rate did not differ significantly from the state rate. ³⁶ During the period 1992–2002, the screening rate in Mercer County was significantly higher than in the state overall. ³⁶ However, screening rates by race within Mercer County are not currently available.

Lack of education (16% of Mercer County women have a high school diploma or less) and poverty (1.5% of county women 45 years and older live below the poverty line) are barriers to adequate healthcare in the county. Black women may not understand the need for follow-up care after an abnormal clinical or mammography screening. Follow-up of abnormal mammograms and improved access to care need to be addressed, and outreach efforts need to be continued.

Underutilization of screening has been attributed to a variety of factors including prevention not being a priority, lack of awareness of risk factors and screening recommendations, and limited access and referral.³⁷ Screening is a key but not sufficient component for reducing incidence and mortality (for all cancers). Appropriate follow-up after an abnormal finding and correct diagnosis and treatment are also critical. According to empirical evidence, in some populations, large percentages of women who have positive mammograms do not receive timely and appropriate follow-up care. Mandelblatt, et al. found that one out of three black women with positive findings on mammograms failed to complete follow-up.³⁸ Inability to pay or poor health coverage, non-white race, educational level, and age (old and young) have all been found to be predictors of poor follow-up.^{39,40,41,42} It is therefore clear that evidence-based interventions designed to improve follow-up are a critical component to reducing mortality from breast cancer.

Cervical Cancer

The cervical cancer incidence rate among all women in Mercer County (9.7 per 100,000) was 11% lower than the corresponding state rate (10.9). Hispanic women had a higher cervical cancer

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^p Some professional organizations set age 40 as the lower limit for routine screening mammography.

incidence rate per 100,000in the county (28.4) than in the state (15.8). Women of all races aged 75+ had a higher incidence rate for the disease in the county (28.5) than in the state (19.6). The cervical cancer mortality rate among women of all races and all ages in the county was similar to that in the state.

Papanicolaou ("Pap") tests detect some precancerous as well as cancerous lesions. Some health insurance companies have moved to cover a more sensitive and specific screening test, the AutoPap, which uses a thin preparation of cells along with computer-assisted technology.²

Human papillomavirus (HPV), a sexually transmitted disease, is the most significant risk factor for developing cervical cancer; recommendations for the incorporation of HPV testing^q as part of a pelvic examination have been developed by the American College of Obstetricians and Gynecologists.^{2,43} Risk factors for cervical cancer include ever being sexually active, lack of routine screening, early onset of sexual intercourse, a history of multiple partners, a history of sexually transmitted infections (especially HPV), obesity, and smoking.

The *Healthy New Jersey 2010* objectives related to cervical cancer incidence and mortality rates are to decrease the age-adjusted incidence rate to 6.8 per 100,000 (with a preferred endpoint of 2.5), and to decrease the age-adjusted death rate to 1.5 per 100,000 (with a preferred endpoint of 0.7), as recalculated using the 2000 U.S. population standard.^{34,35}

The *Healthy New Jersey 2010* objective related to cervical cancer screening is to increase the percentage of women aged 18 and over with intact cervix uteri who had a Pap test within the past two years to 85.0% and a preferred endpoint of 90.0%.³⁴ Data from BRFSS estimated that in 2002 only 54% of New Jersey women 65 years and older had a Pap smear in the past year.¹⁶ In addition, in 2002 21% of women with annual incomes less than \$15,000 and 13% of women with annual incomes between \$15,000 and \$24,999 reported never having a Pap test, compared to 3.6% of women with annual incomes greater than \$50,000.¹⁶

Among 7,689 New Jersey women with no history of hysterectomy who were interviewed from 2000 through 2002, 83% reported having had a Pap smear within the past three years. Based on interviews of 281 women in Mercer County, the county rate did not differ significantly from the state rate. During the period 1992–2002, the screening rate in Mercer County was significantly higher than in the state overall.

Colorectal Cancer

Mercer County's incidence and mortality rates for colorectal cancer by race/ethnicity and gender are comparable to or generally lower than the corresponding state rates with the exception of black men.

• Although black men in the county (69.2) had a lower colorectal cancer incidence rate per 100,000 than either white men in the county (79.8) or black men in the state (77.1), the colorectal cancer mortality rate per 100,000 among black men in the county (46.4) was

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^q For example, the ViraPap[™] will detect which strains of HPV DNA, if any, are present.

- 50% higher than the corresponding county rate among white men (30.9) and 30% higher than the corresponding state rate among black men (35.8).
- Black men in Mercer County aged 65 years and older had a mortality rate of 317.8 per 100,000, considerably higher than the state rate of 210.0.

The *Healthy New Jersey 2010* ³⁴ objective related to colorectal cancer is to reduce the age-adjusted mortality rate per 100,000 to a target of 18.6 for the total population (with a preferred endpoint of 13.0) and to a target of 26.9 for black males (with a preferred endpoint of 13.0), as recalculated using the 2000 U.S. population standard.³⁵ The mortality rate for the disease among black males in Mercer County was more than 70% higher than the *Healthy New Jersey 2010* target established for black males.

Therefore, one population of focus for colorectal cancer education and outreach in Mercer County is black males. The high colorectal cancer mortality rate among black males in Mercer County could be attributed to lack of treatment, lack of compliance with treatment, or lack of access to care affected by education, transportation, or cultural beliefs.

One screening method for colorectal cancer is the fecal occult blood test (FOBT), usually performed within primary care settings and through screening programs, such as those available through the ACS and Brava/CAPS in Mercer County. Treatment is most effective when cases are diagnosed in the early stages; however, only 41% of cases among men and 36% of cases among women in New Jersey were in the early stages at the time of diagnosis. Among 4,961 New Jersey adults aged 50 and over who were interviewed from 2001 through 2002, 56% reported having had colorectal cancer screening (either a fecal occult blood test within the past year or a sigmoidoscopy or colonoscopy ever). Based on interviews of 200 adults in Mercer County, the county rate did not differ significantly from the state rate. Given the low rate of screening, an additional focus on all persons aged 50 and over is appropriate.

Black faith-based organizations may be an effective resource to aid in outreach and screening in this population. Combining colorectal and prostate cancer screening simultaneously (as done in the Brava/CAPS program) is advantageous.

Lung Cancer

During the period 1996–2000, 1,190 Mercer County residents (675 men and 515 women) were diagnosed with lung cancer. In Mercer County, black men and women disproportionately suffer from lung cancer; the incidence rate per 100,000 for the disease among black men (139.0) was 60% higher than the corresponding rate among white men (86.7). Mercer County had the highest incidence rate of lung cancer among black men in New Jersey (18% higher than the state rate, 118.1 per 100,000). In Mercer County, the lung cancer incidence rate among black women (64.1 per 100,000) was 24% higher than the corresponding rate among white women (51.6) and was the third highest incidence rate among black women in the state (24% higher than the state rate, 51.9).

The incidence rate of lung cancer among Hispanic men was 17% higher in Mercer County (78.9 per 100,000) than in New Jersey as a whole (67.2). In both the county and the state, lung cancer incidence rates increase with age.

In New Jersey, the mortality rate due to lung cancer among black men (100.0 per 100,000) was 34% higher than the corresponding rate among white men (74.8). In Mercer County, the disparity in lung cancer mortality was even greater, 63% higher among black men (111.2) than among white men (68.4). With increasing age, lung cancer mortality rates among black men in the county were consistently higher than the corresponding county rates among white men and the corresponding state rates among black men. Among black women, however, this does not hold true. In New Jersey, black women consistently had slightly lower mortality rates for lung cancer than did white women. In Mercer County, the mortality rate for the disease was slightly higher among black women than among white women of all ages, similar among black and white women aged 50 and over, and slightly lower among black women than white women aged 65 and over.

In Mercer County, the death rates per 100,000 due to lung cancer during the period 1996–2000 were 73.3 among men and 37.2 among women. The *Healthy New Jersey 2010* ³⁴ lung cancer objective is to reduce the age-adjusted lung cancer death rate per 100,000 to a target of 47.9 for all males and 40.5 for all females, with a preferred endpoint of 39.7 for the total population, as recalculated using the 2000 U.S. population standard.³⁵ The target lung cancer mortality rate per 100,000 is 45.3 for black males and 41.8 for black females. The county has a long way to go to achieve this target for all males, as well as the target specifically for black males.

Black men and women are the populations of focus for lung cancer, with particular emphasis on black men due to the disparity in lung cancer mortality. The ACS identified the most common cancers among black women are breast cancer, followed by lung and colon and rectum cancers.²⁴ Outreach efforts should be focused on Trenton City and Ewing Township due to their large black populations.

Effective screening and early detection methods are not currently available for lung cancer; most cases of lung cancer are found incidentally or upon presentation of signs and symptoms (shortness of breath, hemoptysis, sentinel nodes, etc). Tobacco smoking is responsible for 87% of lung cancer cases.² Smoking cessation is the best prevention. Smoking cessation programs should be made available for middle-school-aged and older adolescents. Exposure to environmental tobacco smoke (ETS), or "second-hand" smoke, remains an additional important issue.²

Melanoma

The incidence rate per 100,000 of melanoma among men in the county (19.8) was similar to the state rate (20.1) and was lower for women in the county (10.5) than for women in the state (11.9). The mortality rate per 100,000 due to melanoma among men of all races in the county (2.9) was lower than that in the state (4.4). In Mercer County the population of focus is white men. The incidence rate of melanoma among white men in the county (23.6) was similar to the corresponding state rate (23.0). Melanoma risk factors include exposure to ultraviolet light

without protection, sunburn history, fair skin, family history of melanoma, and certain types of moles, termed atypical or dysplastic nevi.² Increasing public awareness and screening should be the focus of efforts to reduce mortality from melanoma.

Oral and Oropharyngeal Cancer

The county incidence rates per 100,000 of oral and oropharyngeal cancer among men (20.5) and women (7.7) were higher than the state rates among men (15.7) and women (6.4). In Mercer County, black men (30.6) and women (12.8) had much higher incidence rates of the disease than did white men (18.5) and women (6.7). Oral/oropharyngeal cancer incidence among men increased most notably from men aged 40 to 49 years (16.2 per 100,000) to men aged 50 to 64 years (52.5). The county mortality rates per 100,000 due to oral/oropharyngeal cancer among men (2.9) and women (1.3) were lower than the corresponding state rates among men (4.4) and women (1.9).

The *Healthy New Jersey 2010* oral cancer objective is to reduce the percentage of oral cancers diagnosed in the late stages of disease to a target of 40% for all males and 35% for all females.³⁴ In Mercer County, 65% of staged cases among males and 57% of staged cases among females were diagnosed in the late stages (similar to the corresponding New Jersey percentages).

A statistically significant higher percentage of oral cancer cases were diagnosed in the distant stage among men in Mercer County (13%) than in New Jersey (7.4%). In addition, a higher percentage of cases were diagnosed in the distant stage among black men in the county (20%) than among black men in the state (9.7%).

The population of focus for oral and oropharyngeal cancer in Mercer County is black men. As noted in Section 2, Trenton has been identified as a medically underserved area for dental health, examinations for which routinely include oral screening. Henry J. Austin is the only dental provider within the county that is a federally qualified health care center; there is a two-month delay in obtaining an appointment. Oral screenings should also be done in emergency departments, by primary care providers, and at hospital admission time for those patients at high risk (tobacco and heavy alcohol users). (For further information, please refer to Section 3 of the full Capacity and Needs Assessment Report¹ regarding access to dental services and trends in heavy alcohol use based on the BRFSS survey data for the state.)

Prostate Cancer

In Mercer County, the incidence rate of prostate cancer was 55% higher among black men (294.6 per 100,000) than among white men (189.7); these rates were similar to the corresponding state rates. Incidence rates for the disease increase with age, particularly after age 50. Among men of all races aged 40 to 49 years, the incidence rate of prostate cancer was 23.1 per 100,000, which increased to 342.1 among those aged 50 to 64 years and to 1,176.5 among those aged 65 to 74 years.

The mortality rate due to prostate cancer among black men (71.3 per 100,000) was more than twice the rate among white men in the county (31.9), a pattern that remains consistent among the

older age groups. Among men aged 50 and over, the prostate cancer mortality rate per 100,000 was 255.4 among black men and 115.3 among white men. Among men aged 65 and over, the mortality rate was 497.7 among black men and 239.2 among white men. A statistically significant higher percentage of prostate cancer cases among black men were diagnosed in the regional (12%) and distant (6.5%) stages than was the case among white men (7.9% of cases in the regional stage and 3.9% of cases in the distant stage). The percentage of prostate cancer cases diagnosed in the regional stage among black men in Mercer County was also higher than the percentage of cases diagnosed at the regional stage among black men in New Jersey (8.6%).

The prostate cancer target established in *Healthy New Jersey* 2010 is to reduce the age-adjusted prostate cancer death rate per 100,000 to 24.7 for all men (with a preferred endpoint of 15.3) and to 56.1 for black men (with a preferred endpoint of 30.2), as recalculated using the 2000 U.S. population standard. In Mercer County, a 21% reduction would be needed to reach the target and a 58% reduction to reach the preferred endpoint for black men.

Clear guidelines or consensus with respect to prostate cancer screening have not yet been reached among the major cancer societies and relevant professional organizations. ^{2,45,46} In the absence of established guidelines, there is an even greater need for community education about risk factors, screening options, and available treatment if cancer is detected. Counseling for men at high risk, such as black men and all men with a family history of prostate cancer at an early age, is critical for appropriate screening. The American Urological Association and the American Cancer Society recommend that physicians should routinely present screening options for early detection and offer the prostate-specific antigen (PSA) blood test and digital rectum examination (DRE) to men at high risk, beginning at age 40 or 45. r,24,47 The population of focus for prostate cancer in Mercer County is black men. According to the NCI maps of medically underserved areas, the older, "baby boomer" population, Hispanic, and other racially diverse populations in Trenton and its outlying areas are in need of screening. Efforts to address this issue have been made in Trenton through the Trenton Crusade and Initiative coalition groups and through the support of the Trenton Mayoral office. However, prostate cancer incidence and mortality rates among black men remain high. Focusing outreach on women who can advise their male family members and friends to obtain prostate cancer screening is one potential way to improve outcomes.

Other Cancer Sites/Issues

HIV/AIDS. The human immunodeficiency virus (HIV) is the etiologic agent of the acquired immunodeficiency syndrome (AIDS) and is associated with the development of several specific cancers (such as Kaposi's sarcoma and non-Hodgkin lymphoma, as discussed further in the NJ-CCCP).² As of June 30, 2003, there were 1,070 persons living with known HIV/AIDS in Mercer County, 63% among men and 37% among women.⁴⁸ HIV/AIDS disproportionately affects minorities; blacks (non-Hispanic) accounted for 56% and Hispanics accounted for 21% of

^r The American Urological Association recommends physicians should routinely offer screening for men with an anticipated lifespan of 10 or more years over age 50, and over age 40 for men with a family history or black men.⁴⁷ The American Cancer Society recommends prostate cancer screening should begin at age 45 for men at high risk, "such as African Americans and men who have a first-degree relative (father, brother, or son) diagnosed with prostate cancer at an early age (younger than age 65)."²⁴

HIV/AIDS cases reported in New Jersey as of June 30, 2003. 49 In Mercer County, 68% of HIV/AIDS cases occurred among the black population. Over 80% of the county's cases were in Trenton alone. 50

Populations of focus for HIV/AIDS-related cancers include the black population, especially in urban settings, criminals (incarcerated or released), the homeless, male-to-male homosexuals, and intravenous drug users. There is a need for continued educational and screening outreach around this issue. The promotion of HIV testing of sexual partners in particular should be emphasized in the Trenton community. Both healthcare providers and patients need to understand the risks.

Bladder cancer. In New Jersey, the bladder cancer^s incidence rate among men (44.9 per 100,000) was 17% higher than the national rate (38.3), and among women, the state rate (11.8) was 18% higher than the national rate (10.0).⁵¹ Incidence of bladder cancer in Mercer County was similar to that in the state for both men and women. In Mercer County, white men had a higher bladder cancer incidence rate (52.1) than black men (17.9) and a slightly higher rate compared to white men in the state (48.2).

Mortality due to bladder cancer was also higher in New Jersey than in the nation overall. The American Cancer Society estimated that bladder cancer in 2003 would be the sixth most common cause of cancer mortality in the U.S. and fifth most common in New Jersey.⁵² Mortality rates for the disease were similar in New Jersey and Mercer County. Bladder cancer seems to be associated with smoking, exposure to toxic substances, age, race (white), and high-fat diets.²⁴

Section 4 – Discussion, Analysis and Recommendations

Recommendations for County and Local Priorities

- Fund additional research focused specifically on areas with larger minority groups and areas with high poverty rates (e.g., Trenton) to investigate incidence, mortality, and the resources available, cancer screening capacity in particular. (NJ-CCCP Goal BR-4, Objectives BR-4.1, 4.2, PR-5.1, Strategy LU-6.1.2)^t
- Evaluate what primary healthcare providers are doing to promote cancer prevention, education, screening, and treatment.
- It has been suggested "a celebrity spokesperson can have a substantial impact on public participation in preventive care programs." Trenton has relied upon Mayor Palmer to promote prostate cancer screening; identifying black celebrity role model(s) for breast cancer and lung cancer should be explored.

Statistics: 2001 Incidence and Mortality Web-based Report" footnotes at http://apps.nccd.cdc.gov/uscs/TableV.asp?group=1a&Year=2001&Gender=FEM&RateType=AgeadjType&TableType=INCI#Footnotes

^t References in parentheses are to relevant goals (e.g., BR-1), objectives (e.g., BR-1.1), or strategies (e.g., BR-1.1.1) outlined in the NJ-CCCP.

- Continue to build political support to secure greater financial commitment of healthcare dollars to provide screening and early treatment for the uninsured, as a long-term recommendation.
- Encourage existing Mercer County health coalitions to work with outreach and education programs at the cancer centers in the region to increase awareness about the NJ-CCCP and the Mercer County Cancer Capacity and Needs Assessment Report, with emphasis on identifying and addressing the most significant barriers confronted by the poor, working poor, and minorities to access to prevention education and screening services. Transportation and literacy needs of these populations should be taken into consideration in making these services as convenient to use as possible. (AC-2.1.5-7, AC-4.2.1-6)
- Promote clinical trial participation, particularly among black and Hispanic populations, related to all cancer sites. (BR-5, BR-5.1; CE-5, 5.1, 5.2; CO-3, CO-3.1, CO-3.2; LU-5, LU-5.1; PR-5, PR-5.1, 5.2, 5.3)

Recommendations for Statewide Priorities

Evaluation and Development of Federal/State NJCEED Model Program. Recommend to the Office of Cancer Control and Prevention that they support the statewide evaluation of the experiences of the county NJCEED programs in order to:

- Develop a set of best practice strategies that have helped narrow gaps in services due to health disparities, increased screening registration in NJCEED programs, attracted men for prostate cancer screening, etc. (AC-1, AC-4)
- Inform and update primary healthcare providers and the cancer centers in the county about the services of NJCEED. (AC-4.2)
- Develop a "toolkit" of county-level resources for NJCEED programs that draw on evidence-based programs. (AC-4.1, 4.2)
- Advocate for increased NJCEED program funding to cover dental visits for oral cancer screening (OR-2.1) and to expand screening to include more of the uninsured and underinsured population (those who may have income levels above the NJCEED limit). (AC-1.2.3)

Insurance Issues. The BRFSS reports that an estimated 13% of adults in New Jersey did not have any kind of healthcare coverage in 2002. The New Jersey Primary Care Association also estimated that approximately 13% of Mercer County residents were uninsured in 2000. Applying this percentage in Mercer County would suggest that 35,434 adults in the county lack such insurance. The actual number of uninsured residents in Trenton City may be higher than 13% of the city's population due to the lower median household income, higher rate of poverty, and higher percentage of unemployment. Therefore, it is recommended that state-funded health insurance coverage should be expanded through such mechanisms as incremental increases to child healthcare programs and tax incentives to small businesses to cover employees for appropriate cancer screening, etc. In addition, a federal/state model for full funding of uninsured groups for cancer prevention, cancer screening, early detection, and complete treatment and after care should be endorsed. (AD-1.2.2, AD-2.1-2).

- Treatment for prostate and colorectal cancer should be covered by Medicaid.
- Increase reimbursement rates to hospitals for indigent care provided, which would free up funds to conduct more hospital-based interventions, such as oral cancer education and screening and chemotherapy programs.
- Increase Medicaid reimbursement levels for primary care visits and screening
- Utilize revenue from tobacco taxes for cancer screening and smoking cessation programs.

Recommendations for Interventions Based on Research-Tested Intervention Programs

The priorities in Mercer County, based on the order of magnitude of the cancer burden, are lung, prostate, breast, and colorectal cancer, with black men and women as the primary population of focus. Bladder cancer among white men is a growing concern; primarily linked to tobacco use, the incidence of bladder cancer can be reduced through lung cancer initiatives to reduce smoking.

Recommendations Appropriate for All Cancer Sites

- Utilize a celebrity to promote site-specific cancer awareness.⁵³
- Based on geographic areas of medically underserved residents identified by the NCI's
 Consumer Health Profiles, retailers close to Trenton such as Payless Shoes, Target, WalMart, and Burlington Coat Factory should be approached to support a cancer screening
 bus or mobile van initiative.
- Contact food corporations to become partners in outreach. Wegmans supported a food cultural event in Pennsylvania for cancer in the spring of 2004; similar events could be hosted in Mercer County Park or on the Waterfront in Trenton.
- Continue outreach with and to black faith-based organizations, such as Reverend Justice's group, which has been extremely active and proactive in addressing the Trenton cancer burden through the Trenton Cancer Initiative.
- Seek support from county corporations and grant foundations to implement voucher programs for childcare, transportation, and screening programs.
- Develop, as necessary, educational material in various languages (Spanish, Polish, Eastern European, and Asian languages) and disseminate at cultural events in Trenton and Mercer County, e.g., Heritage Days in Trenton.
- Fund evaluation of evidence-based interventions designed to increase education, prevention, screening, follow-up, and tobacco (all kinds) cessation, including state and local tobacco and alcohol control laws and ordinances.
- Review research-tested interventions conducted at the primary care level to identify the most effective practices for follow-up, counseling, and referral.

Recommendations for Specific Cancer Sites

Lung Cancer. NJ-CCCP Goal LU-1: To adopt the goals of the New Jersey Comprehensive Tobacco Control Program, by Objective LU-1.1 to increase funding. The following strategies are addressed:

- Strategy LU-1.1.2 Support an increase in the state tobacco tax.
- Strategy LU-1.1.4 Increase the awareness of state-sponsored tobacco treatment resources in communities. The older, inner-city, Hispanic and black minorities have the highest need for multilingual smoking cessation programs in underserved communities (Trenton, Ewing, and Hamilton). Healthcare providers need continuing education for smoking cessation referral, guidelines, and programs.

Fichtenberg and Glantz evaluated nine existing studies and found that "no detectable" relationship existed between merchant compliance with the laws and smoking prevalence among young people who were the target of the laws. ⁵⁵ Nor did they find a difference in smoking rates between towns with and without laws restricting youth access to smoking tobacco. Given the expense of youth access restriction programs and the paucity of resources generally available for tobacco control, the authors concluded, "... tobacco control advocates should abandon [the strategy of youth access restriction] and devote the limited resources that are available for tobacco control toward other interventions with proven effectiveness." ⁵⁵

Researchers found that although nicotine replacement therapy increased cessation rates (consistent with existing evidence from other research), interventions that included contact during admission and follow-up increased cessation rates regardless of whether nicotine replacement therapies were used. ⁵⁶

- Recommendation #1. Promote smoking cessation programs with face-to-face counseling and nicotine replacement therapy.
- Recommendation #2. Implement mandatory education on interventions for smoking cessation in the curricula of all medical, dental, and other health-related professional schools to train future physicians, physicians' assistants, nurse practitioners, dentists, dental hygienists, etc. In New Jersey, two out of three adults reported being asked their smoking status by their clinician and more than one-half were advised to quit.²

Prostate Cancer. NJ-CCCP Goal PR-2: To improve patient education about prostate cancer screening, risk factors, symptoms, follow-up, and treatment. Strategies are:

- *Strategy PR-2.1.2* Ensure that distributed educational materials on prostate health and screening are up-to-date.
- Strategy PR-2.2.1 Obtain available prostate cancer educational materials that explain in detail the next step after an abnormal screening test (DRE or PSA).

The results of one recent study suggests the use of a videotape is more likely to enhance knowledge and facilitate shared medical decision-making regarding screening with the PSA test in men 50 years and older, compared to internet-based decision aids. ⁵⁷ This finding is especially relevant for three populations of focus: black men, Hispanic men, and the elderly. Black men and

Hispanic men in Mercer County are more likely to have lower incomes, which is a greater barrier to owning a computer than a VCR, and older men are less likely to try accessing this information from the internet, a medium that may be perceived as too complex or too much trouble compared to now widely used videotape technology.

Other researchers found men assigned to scripted informational intervention were less interested in getting a PSA test than men assigned to receive the single sentence about the PSA test, and were 56% less likely to indicate "high interest" in being tested.⁵⁸

Recommended Strategies

- Public health messages addressing prostate cancer with a celebrity spokesperson to promote specific cancer site awareness. 53
- Community events such as prostate/men's health clinics.
- Focus on black men through black businesses, churches, local barbers, and events with large male audiences (e.g., sporting events).
- Post-screening database development (funding for use in clinics with a large percentage of low-income people) to prevent patients from being lost to follow up.

Breast Cancer. NJ-CCCP Objective BR-1.3: To develop and disseminate breast cancer educational materials and resources to increase knowledge, improve public understanding of the value of screening and early detection, and promote high-quality breast health, paying special attention to vulnerable, high-risk populations.

- Strategy BR-1.3.3 Identify existing, and develop as needed, breast cancer educational materials that are translated into multiple languages as appropriate. Of importance to Mercer County are Spanish, Eastern European languages, Russian, Asian Indian, and East Asian languages. There remains a need for materials in French Creole and certain West African languages within some communities of Trenton and Ewing. DVDs and videos should be utilized.
 - o *Recommendation #1*. Collaborate with the Eric B. Chandler, CASE program (Rutgers, New Brunswick, NJ), which encourages college students to become involved in volunteerism. One of the areas through this grant-funded program is to target bilingual students and have them serve as translators in hospitals, clinics, and schools.
- Strategy BR-1.3.5 Organizations should seek out professionals from various ethnic communities to provide breast cancer education and outreach.
 - o *Recommendation* #2. Consider disseminating informational materials through WIC programs, faith-based organizations, and school flyers to reach minority women.
- Strategy BR-1.3.7 Distribute information regarding NJCEED sites, and other sites regarding no-to-low-cost breast cancer diagnostic and treatment services for uninsured women in the community.

- o *Recommendation #3*. Develop a pamphlet listing facilities, costs, and most importantly hours and transportation available for use by clinics, healthcare practitioners, and outreach workers.
- o Recommendation #4. Stress mammography screening.
- o *Recommendation #5*. Implement two research-tested interventions, as described below, which would apply to the higher percentage of lower income and minority populations in the Trenton area.

Many effective patient-based approaches exist. Two examples include recently evaluated interventions that employ two comparatively low-technology mechanisms, direct mail and the telephone.⁵⁹

- "Tailored telephone counseling" to increase screening mammography in the general population. Counselors contacted women who had not had a mammogram in the previous 15 months and, if contact was made, the counselors delivered the tailored counseling. An active control received instead a mailed reminder only. Women in the intervention arm in the first HMO were 30% more likely to have a mammogram than controls in one HMO. In the second HMO intervention women were 20% more likely than controls to have a mammogram. The authors calculated that due to the intervention, for every 10.9 women eligible for counseling one additional woman was screened. A clear drawback of this approach in a low-income setting is that some women may not have telephones, or may have uneven telephone service.
- Friend-to-Friend (FTF) is a multidimensional community-based intervention to increase mammography utilization among low-income women living in public housing high-rise apartment complexes. This program would be most useful for the black population in Mercer County, as it is estimated that 39% of Trenton's residents lived in housing structures of two units or greater and approximately 12% lived in housing with 20+ units in 2000. The telephone counseling program identified above would also be useful; however, uneven phone service may affect this.

In conclusion, the recommendations for breast cancer are:

- Link screening with cervical cancer screening.
- Develop a brochure listing mammography programs, costs, transportation, ages, insurance or uninsured status.
- Recruit and train outreach workers bilingual in African languages, French Creole, Spanish, and Polish and other Eastern European languages.
- Explore the Friend-to-Friend program identified above for implementation in the City of Trenton especially.
- Consider telephone follow-up and counseling, utilizing a database within NJCEED programs to remind patients.
- Conduct outreach to assisted-living and 55+ retirement communities in the county; collaborate with local public health departments and religious organizations. Hadassah of New Jersey Southern Region (Princeton, NJ) is most interested in doing the "check it

out" program targeted at the teenage audience especially in the low-income areas for teaching breast self-examinations.

- Support legislation for mammography payment coverage on a sliding scale.
- Suggest monitoring program for documentation of initial mammogram and for follow-up
 of any abnormal findings to reduce failures to return for further diagnosis of abnormal
 results of initial screening.^{u,38}
- Stress to primary care practitioners that they should prescribe mammograms annually for patients aged 50 and over, as many of these patients do not see a gynecologist after childbearing years.

An Institute of Medicine report has suggested additional strategies to improve capacity and utilization; v₃7 addressing the relevance to Mercer County is beyond the scope of this summary.

Colorectal Cancer. NJ-CCCP Goal CO-1: To raise awareness and knowledge about colorectal cancer for all residents of at least high school age by 2006.

- Develop educational interventions to promote healthy lifestyles and disease prevention, including modification of risk factors, such as diet, physical exercise, and smoking and alcohol use. (CO-1.2.3)
- Develop educational materials. (CO-1.2.3)
- Focus on providing education and or screening for women aged 40 to 50 years, black men and all older adults. (CO-1.2.3)
- Support the need to continue Mercer County NJCEED program for services for the underserved and the uninsured. (CO-1.2.3)

Recommended Strategies

- Increase the proportion of those aged 50 or older who have received a fecal occult blood test within the past year and/or have ever undergone a sigmoidoscopy or colonoscopy.
- Promote community awareness through community events to include colorectal health clinics. (CO-1.2, CO-1.2)
- Prevent patients from being lost to follow-up; database development should be explored.
- Promote healthier lifestyles. Researchers found that people receiving coupons increased fruit and vegetable consumption behavior, and education affected attitudes about

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^u Although there are a substantial number of false positive results on screening mammography, follow up is important to ensure proper and timely diagnosis.

Yamong these are: (1) to specially train non-physician workers to prescreen mammograms (not replacing radiologists) but utilizing the British system of certifying radiology technicians, so more scans can be completed and additional views done the same day; (2) to use computer programs to double-check the x-rays; (3) to conduct mammograms at multiple sites, increasing the number, but have centrally grouped radiologists conduct final review after the radiology technicians perform the first review. Other authorities, including the American College of Radiology, consider at least some of these recommendations controversial or unfounded.

- consuming more fruits and vegetables and increased consumption in an evaluation of a 5 a day fruit and vegetable program in one Michigan County. ⁶¹ (NP-1)
- Take advantage of the large school-aged populations in Mercer County regarding this and other cancers as an excellent starting point for preventative cancer understanding.
- Gain support for funding for "Body and Soul" program using faith-based organizations to provide education for disease prevention (pilot program in Mercer County).

Men can be reached through information disseminated at sports clubs and events, barber to client program, community fairs such as the Heritage Festival in Trenton, and through nutritional programs.

Cervical Cancer. NJ-CCCP Goal CE-1: To improve access to cervical cancer screening. The objective is to locate populations not being screened for cervical cancer on a county level (CE-1.1).

Recommended Strategies

- Strategy CE-1.1.1 Use Geographic Information Systems technology and other appropriate data to locate population subgroups with a high risk for developing cervical cancer. The NCI cluster maps indicate Trenton, Hightstown, and Ewing are the areas in need of breast and cervical cancer screening. Seniors located in one section of Hamilton where there is a 55+-retirement community are in need of screening.
- Strategy CE-3.1.3 Develop and distribute a resource listing of cervical cancer information sources (including clinical trial information) to all medical facilities on an annual basis. In Mercer County, all YWCAs, health clubs, women's clubs should also receive this information.
- Strategy CE-1.1.2 Identify barriers to cervical cancer screening.
- *Strategy* CE-1.2.1. Develop informational materials in different languages and venues as a short-term goal for increasing access to screening.

NJ-CCCP Objective CE-4.1: To educate healthcare professionals about the importance of cervical cancer, screening, risk factors, follow-up, treatment options, and cultural sensitivity.

• Strategy CE-4.1.4 – Review the methods that different medical facilities and laboratories use to notify patients of their Papanicolaou ("Pap") smear results. Determine the method easiest for patients to understand (using a randomized controlled trial with a mix of patients that include black, Hispanic, and young women as trial participants), and share the study results with all medical facilities and laboratories for possible implementation. Survey appropriate medical facilities for the use of an evidenced-based follow-up/diagnostic Pap test reminder. Based on survey findings, identify and encourage the appropriate medical facilities to use an evidenced-based Pap smear reminder system appropriate for their patient base.

In conclusion, the recommendations for cervical cancer are:

- Link screening with breast cancer screening.
- Recruit and train multilingual outreach workers, especially Spanish speakers, to reach the population with the greatest cancer burden. (CE-2.1.1, 1.2)
- Educate school-aged girls regarding STDs. (CE-2.1.3)
- Use mobile vans to reach residents unable to access medical facilities due to transportation, language, or socioeconomic barriers. The Friend-to-Friend program provides peer support and endorsement of cancer screening. (CE-2.1.2)
- Evaluate vouchers for transportation, childcare, and Pap smear screening to target the underserved population

The interventions to increase screening for breast cancer using computerized reminders, telephones, or outreach to the underserved community are all relevant to cervical cancer (and all other cancers except lung cancer). A study of the effectiveness of the intensive follow-up program versus the voucher was conducted in two large public hospitals and involved 1,453 mainly Hispanic women who were married and with no source of payment for care, and no usual care. The intervention had two plans; one involved implementation of a protocol designed to increase follow-up that included direct multiple attempts by mail and telephone to contact the patient. The second intervention involved vouchers provided to offset the cost of follow-up visits due to out-of-pocket expenses. Patients were randomly assigned to receive intensive follow-up, the vouchers, a combination of both, or to a usual-care control group. Just over 8% more women returned for a follow-up visit 4 to 6 months (the time period of the primary endpoint) after an abnormal Pap smear in the intensive follow-up arm than in the control arm. In the voucher arm, 7.1% more women returned for follow-up compared to the usual care control group. No interaction effect was present in the combined interventions arm. Thus, the telephone-and-mail intervention was more effective than a voucher-only program. The researchers also found that factors increasing the likelihood of loss to follow-up were younger age, black race, unmarried status, and less severe abnormality of Pap finding. 62 This is important for Mercer County due to the underserved population of blacks and Hispanics in mostly Trenton.

Oral/Oropharyngeal Cancer. The first step in reducing the oral cancer burden in Mercer County is to provide dental services to medically underserved areas. Mercer County has been designated as a medically underserved area for dental health and primary care, as noted previously, especially in the Trenton area. Some strategies at the county level include recruiting new dentists with financial incentives (e.g., forgiveness of educational loans) to establish practices within these areas and providing sliding-fee scales. At the state level, contracts with employers should be promoted, as well as establishment of MUA dental grants and providing oral cancer screening guidelines to primary care gatekeepers (PCPs, hospitals and clinics).

Closing Remarks

In summary, although there are numerous other considerations in the county, funding of programs that can improve access to healthcare and preventive interventions, and education of

the consumer about healthy lifestyle choices will be the most useful. To address the needs and resources of the county the Cancer Capacity/Needs Assessment was compiled.

The Cancer Capacity and Needs Assessment provides a detailed baseline assessment for Mercer County. The data, interpretations, and recommendations in this report were developed to provide a wide array of public health and medical personnel with standardized information and detailed analyses that can help guide and focus their efforts at the county level, including such local health initiatives as the forthcoming Community Health Improvement Plans. The reports from all of the counties will collectively inform the continuing comprehensive cancer control efforts of the Office of Cancer Control and Prevention of the New Jersey Department of Health and Senior Services; the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey; and the University of Medicine and Dentistry of New Jersey.

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